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Bill Number: 5076
Title of Bill: An Act Concerning Appropriation for a Fetal and infant Mortality Review Program
Author of Bill: Representative Dillon, 92nd District
Testimony by: Brian D. Karsif, MD, FACOG, MPH
Coordinator, Greater New Haven Regional FIMR Project
Yale New Haven Hospital, Attending Physician, Women's Center
Chairman, CSMS Committee on Maternal Mortality
DPH Contractor for Pregnancy-Related Mortality Surveillance
Committee: Public Health Committee

My name is Brian Karsif and I am an OB/GYN physician and the Coordinator of the Greater New Haven Regional FIMR Project and I wish to thank members of the Public Health Committee for permitting me to provide oral and written testimony in support of this bill today.

First, I think it makes sense to offer a quick summary of what FIMR is and what it is not.

As stated in a review of FIMR by the United Health Foundation in 2006, "The overall goal of FIMR is to enhance the health and well-being of women, infants and families by improving the community resources and service delivery systems available to them. Through FIMR, key members of the community come together to review information from individual fetal and infant deaths. The purpose of these reviews is to identify the factors associated with these deaths, determine if they represent system problems that require change, develop recommendations for change and assist in the implementation of change."

To clarify, there are over 200 FIMR programs nationally and 5 such projects in the State of CT. At present, each of our programs is being funded at \$25,000 per site for all program expenses including a single paid coordinator. The 5 current sites are Greater New Haven, Windham-Willimantic, New Britain, Manchester-Vernon and Hartford. The main function of the FIMR coordinator is to present cases of fetal and infant deaths to a Case Review Team comprised of local and regional volunteers. The cases are synthesized by reviewing and abstracting the medical records for the mother and baby and then interviewing the mother and family whenever possible. Most of the volunteer members of our CRT's are in some way connected with local, regional, statewide or even national MCH issues: some are obstetricians like myself, pediatricians, social workers, public health researchers, academicians, members of local health departments, legislators, teachers or representatives of school boards, nurses, psychologists, psychiatrists, clinic managers, or members of municipal or governmental agencies like the police or DCF. We also have representatives from Planned Parenthood, and other non-profits like Hygeia and CT Voices for Children. The function of the CRT is to review the cases presented by the Coordinator and after careful consideration, provide recommendations for local, regional or perhaps statewide interventions to a 2nd volunteer board, the Community Action Team or CAT, whose role is to attempt to translate the CRT's recommendations into interventions aimed at accomplishing the FIMR goals.

Our 2006-07 DPH contracts state under the 'Activities' section of the 'Deliverables' that, "The contractor shall collaborate with the CAT to develop a formal, written, community action plan for addressing prioritized community action resources and service delivery

changes as needed, to improve birth outcomes." The committee should be aware that the main reason we are supporting this piece of legislation is that each year for the past three, the Department of Public Health has sought to de-fund and eliminate the FIMR programs in large part because we have not been able to adequately meet our goal of "...improving birth outcomes." I suggest to you that, given the enormous number of medical, psychosocial, cultural, economic, racial, ethnic, and genetic factors that impact on pregnancy and neonatal outcomes, it is simply not possible to expect our little FIMR programs to produce measurable improvements in local or regional birth outcomes directly attributable to our work. The current funding covers the costs of running 5-10 yearly meetings that include food for 10-20 people at each meeting, printing costs for brochures and other pamphlets, travel expenses for the Coordinator, funds to attend a conference, funds for interventions, funds for a data manager, overhead for the fiduciary and finally salary for the Coordinator. No standard mechanism exists whereby we can enlist DPH financial and/or technical assistance in implementing CRT and CAT-driven interventions and, in fact, we have been specifically encouraged to find complete funding for our program costs elsewhere. Those of us involved in our programs, however, believe that the FIMR program is one of the most important maternal and child public health initiatives in the state at the moment and considering the nominal funding, the list of our accomplishments is absolutely incredible, and a partial list is submitted along with this testimony.

But if we are unable to directly and measurably impact birth outcomes, what is it that we can accomplish? To cite the United Health Foundation report again, "The recent findings of the national evaluation of FIMR indicate that this process is an evidence-based effective perinatal systems initiative. The evaluation also documents that local health departments sponsoring FIMR compared with those without FIMR were more likely to report six improved core public health functions:

1. Data collection and analysis
2. Client services and access
3. Quality improvement for systems of care
4. Partnerships and collaboration
5. Population advocacy and policy development
6. Enhancement of the labor force."

In addition, "Three components of the FIMR process are especially valuable in discovering and addressing community factors related to infant health disparities:

1. The diverse coalition/community partnership building component of the process,
2. Inclusion of the voice of local families who have lost their babies, and
3. FIMR actions based on decisions pertaining to the whole community and the families who live there

So in fact, through creation of these community partnerships, we do impact on a number of important public health functions and help drive a variety of local and regional initiatives aimed at enhancing the health and wellbeing of women, infants and families and thereby likely impact indirectly on birth outcomes.

Please allow me one final minute to comment on the Title V Perinatal Health Plan for the State of CT. As you know, every five years, DPH is obliged, by mandate of the Title V funding requirements of the Maternal Child Health Bureau, to create a new plan for spending the Federal Title V MCH dollars, thus the 'Perinatal Health Plan,' that specifies MCH goals and objectives according to a number of National and State Performance

Measures. The most recent Plan was submitted to the MCHB in July 2005 and covers the period from 2005 through 2009.

I was one of those who participated in the 'Perinatal Health Advisory Committee' that helped DPH create this plan. So when I reviewed the final document, I saw that Goal #6 – 'Reduce recognized birth-related risk factors for children with special health care needs' - specifically includes FIMR as one of the groups to be involved in this work. FIMR's involvement in this goal is to "Decrease the number of premature births...through collaboration with DPH, CSMS and local health departments" and the specific work is to "Identify local and regional risk factors through collection and analysis of...birth outcomes data," something the FIMR projects are currently already doing. In addition, the plan seeks to "Create and implement local and regional prevention strategies aimed at preventing premature births based on risk identification..." obtained from the data analysis noted above. Again, this is also some of the work in which our FIMR groups are currently involved. We should keep in mind, however, that the March of Dimes as well as many other organizations, is currently spending many millions of dollars annually seeking to better understand the risk factors that contribute to preterm births in order to create interventions aimed at reducing the incidence of these births.

Finally, when I review the 9 goals stated in the 'Perinatal Health Plan,' it's easy to see how FIMR cuts across all 9 of these goals and contributes effectively to every single one. To better understand this, I would need additional time to review work specific to the 5 different FIMR groups and describe how specific programs address one or more of the 'Perinatal Health Plan' goals, but suffice it to say, our FIMR programs can effectively contribute to meeting all 9 goals delineated in the Perinatal Health Plan.

In short, we five FIMR Coordinators believe it is imperative for the legislature to, at a minimum, institutionalize FIMR within DPH and re-fund the current 5 FIMR programs so as not to lose the valuable consortia created at each site. But we also recognize the potential for similar work to be accomplished elsewhere in the state by creating and funding additional FIMR programs in areas of the state where high rates of fetal and infant mortality exist. We are also seeking additional financial and technical support from DPH to collaborate with us more closely than in the past to facilitate creation, implementation and evaluation of local, regional and statewide maternal and child public health interventions based on recommendations derived from ongoing FIMR CRT and CAT work. We are eager to work with DPH to expand the range and scope of FIMR in the state to further enhance the wellbeing of our women, infants and families.

Thank you for your consideration.

Department of Public Health
Perinatal Health Plan for Connecticut, 2005-2009
Perinatal Health Plan Goals

1. Reduce perinatal health disparities, particularly preterm/low birth weight births and infant and fetal mortality between and among racial and ethnic groups.
2. Improve access to a continuum of health care services for underserved and/or un-served women of childbearing age.
3. Enhance and encourage male involvement in the continuum of women's health care from preconceptional, prenatal through postnatal periods.
4. Reduce pregnancies and poor birth outcomes among adolescents.
5. Reduce unintended pregnancies for all women.
6. Reduce recognized birth-related risk factors for children with special health care needs.
7. Improve the state's system capacity to collect high quality maternal child health data and disseminate in a timely manner.
8. Improve access to mental health, substance abuse treatment and dental health services which can improve the overall health for pregnant and postpartum women.
9. Improve inter-provider communication strategies regarding perinatal health care delivery.

ACCOMPLISHMENTS Greater New Haven Regional FIMR Project 2003-2006

1. Expanded FIMR program to include Quinnipiac Valley Health District (now 4 health depts)
2. Developed the CT FIMR ACCESS-based database for abstraction of medical records of fetal and infant deaths for improved consistency of mortality surveillance and review.
3. Introduced, initiated education and guidelines for high risk FIMR communities to implement the CityMatCH's Perinatal Periods of Risk (PPOR) data analysis tool intended to be utilized for a more regional and statewide approach to compliment fetal and infant mortality surveillance and review.
4. Instrumental in facilitating local health authorities to establish a regionalized approach to utilize PPOR analysis tools to more effectively address perinatal health disparities.
5. Created project-specific brochure to be distributed to pediatrician's and obstetrician's offices to aid families who have experienced a loss.
6. Arranged with the YNHH L&D staff to place the brochures in the Memory Box distributed to families who have experienced a loss.
7. Collaborated with DPH to provide input to and support the Perinatal Depression grant application (March 2005) and program run by DPH and the New Haven Health Department.
8. FIMR coordinator participated in the Medicaid Managed Care Forum on dental care, depression and perinatal outcomes March 2006.
9. FIMR coordinator participated in DPH Fatality Conference May 2004 as keynote speaker and panelist.
10. FIMR coordinator facilitated creation of a FIMR program with PPOR in the Naugatuck Valley Health Department out of Griffin Hospital.
11. Created Bereavement Fund at the Hygeia Foundation to provide funds to help bury a stillbirth for families who have experienced a fetal loss. Created and implemented fundraiser for Fund and raised ~\$3000. Distributed \$600 over 6 families. A board of directors was created who then wrote guidelines for distribution of the funds.
12. Provided birth/death data, analysis to New Haven Healthy Start's Perinatal Partnership.
13. Developed and contributed to the enhancement of the YNHH L&D to VNA referral system for families who have experienced a loss.
14. Reviewed with DPH Vital Records staff, New Haven Vital Records, and YNHH L&D staff issues around accuracy of birth and death certificate completion, accuracy of state birth certificates. New research project begun June 2006
15. Several meetings were held with members of the New Haven Healthy Start Consortium to begin formation of a CAT based on this group at its core. One formal CAT meeting was held at which time an educational session was held utilizing the expertise of Dr. Eve Colson, a Yale pediatrician with research and clinical work in SIDS. The discussion concerned back to sleep, SIDS, sleeping arrangements.
16. New qualitative research project begun June 2006 and ongoing re: bedsharing and SIDS.
17. Facilitated NHHD Women's Health Director presentation of New Haven fetal and infant mortality program activities at the August 2004 National FIMR Conference.
18. Coordinator conducted multiple educational programs and grand rounds regarding FIMR, PPOR, and prematurity at several regional hospitals.
19. Coordinator videotaped a piece for the Latino New Haven local access TV station on prematurity and its consequences.
20. Live birth, fetal death, infant death, and linked live birth-infant death files were obtained for all 8 towns in the project from 1990 through 2004.
21. More in depth analysis of preterm birth data performed (PPOR Phase II) providing a better understanding of most important risk factors for preterm and VLBW births in our cohort.
22. A relationship has been created between the FIMR group and the nurse manager in the YNHH Newborn Special Care Unit. Plans are underway to work with this nurse manager to create a network for notification of the FIMR coordinator of all infant deaths up to one year

that occur in the NBSCU or the PICU at YNHH in order to enable better coordination of bereavement services after the family goes home.

23. Coordinator provided educational session to Windham FIMR re: chorio-amnionitis and its impact on preterm births.
24. Coordinator involved in research at Yale Department OB.GYN regarding exercise and pregnancy outcome
25. Coordinator involved in New Haven Teen Pregnancy Prevention Task Force.
26. Coordinator part of Office of the Child Advocate's Child Death Review panel.